



Original research article

# “I need you to pick him up.” Next of kin’s experiences with social support in dementia

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## Abstract

**Introduction:** Demographic changes entail an increasing incidence of dementia. Next of kin experience challenges in health due to a mismatch between social support and burdens of care in everyday life. The aim of the study was to contribute to knowledge about what characterises the experience and learning of social support among the next of kin of people with dementia – and how this experience can be understood.

**Methods:** The study used a qualitative research design. The sample contained thirteen persons participating in three focus group interviews, six women and seven men in different next of kin roles, experiencing different phases of dementia, and from both rural and urban municipalities in Norway. The study was approved by the Norwegian Centre of Research Data and informed consent obtained from all participants. The transcribed interviews were analysed using narrative analysis with four main readings.

**Results:** The participants focused on their entire life situation. They pointed to extensive changes in their life situations over a long period of time, where the need for social support persisted and changed. Three thematic characteristics of social support have been analysed: *Acknowledging dramatic change; Ensuring the right help at the right time; and Self-taught social support.*

**Conclusions:** Based on the results of the study, a life course perspective, continuity, and focus on communicative competence in enhancing social support are central to the experience of social support for the next of kin of people with dementia.

**Keywords:** Dementia; Focus group; Next of kin; Qualitative method; Social support

## Introduction

Demographic changes have led to an increased proportion of elderly people and an increased incidence of dementia in the population. Dementia is a chronically progressive disease that causes increasing needs for assistance. Next of kin provide as many man-years of care work as the public welfare services. At the same time they have to take care of their own needs and participate in society (Brunvoll, 2017; Engedal and Haugen, 2018). In public welfare guidelines, increasing emphasis is placed on living in one’s own home for as long as possible. The importance of acknowledging and supporting next of kin is emphasised (Norwegian Ministry of Health and Care Services, 2018, 2020a, b; Smebye, 2020; World Health Organization, 2017).

The next of kin of people with dementia have more extensive health problems, physically, mentally, and socially, than the general population (Adelman et al., 2014; Sagbakken et al., 2018; Tretteteig et al., 2017). Research points to the importance of social support to ensure quality of life and health for both relatives and people with dementia (Bökberg et al., 2015; Kjällman et al., 2014). Next of kin lack social support in the

sense of recognition, relief and help in everyday life from public welfare services (Carlsen and Lundberg, 2017; Strøm and Dreyer, 2019).

Social support is a complex phenomenon that refers to cultural and relational qualities and characteristics of social networks as part of work-affiliation, local communities, groups and individuals. Social support involves help, protection and care given to other people and includes psychological, emotional, and spiritual support; informative, guiding, and advisory support; as well as instrumental and practical assistance (Eisenberger, 2013; Schiefloe, 2015).

Social support has both a buffering effect and direct significance (Schiefloe, 2015). It contributes to better quality of life, health and participation in society through recognition, development of relationships and belonging, and helps to increase resilience, knowledge and coping in everyday life as well as during life events (Kokko and Hänninen, 2019; Lepore, 2012). The ability to experience, receive, adjust and contribute valuable social support includes interaction and communication. The benefit from available social support is related to the recipient’s changing needs and the donor’s ability in individual adaptation and mobilisation (Kokko and Hänninen, 2019).

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Social support is provided through various individual and group-based support programmes and psychosocial interventions. In support groups, experiences, learning and solutions are discussed in an atmosphere of emotional support (Carter et al., 2020; Taylor, 2011). Extensive scientific studies of various support programmes show inconsistent results. However, several studies emphasise the importance of access to various forms of support, adapted to families' unique situations (Clemmensen et al., 2019; Strøm and Dreyer, 2019; Tomar et al., 2019).

With this background, the aim of the study was to contribute to knowledge about what characterises the experience of social support in the next of kin of people with dementia, and how this experience can be understood.

## Materials and methods

The study had a qualitative, narrative design based on three focus group interviews. Focus group interviews represent participants' varied experiences, and support associations, variations and different aspects of experience on a selected topic (Wilkinson, 2016). Narrative as a method provides an opportunity to access complementary descriptions of experiences and learning. Furthermore, insight is provided into participants' experiences of challenges and breaches of expectations, as well as their assessments of the experience described (Riessman, 2008).

### Sample

The participants in the study were recruited through leaders of training programmes for next of kin, nursing homes and care homes by e-mail and letter. The inclusion criterion was that participants had to be next of kin of persons with dementia. The latter could be in different phases of dementia, and of either sex. After confirming their interest in the study, all participants were telephoned and given oral information and sent information letters with a form for declaring consent. The sample was six women and seven men, comprising eight spouses, one mother and one father, two daughters and one sibling, see Table 1. The participants were from four different Norwegian municipalities, both urban and rural. Of the participants' family members with dementia, seven lived in nursing homes, one in a care home, another in a short-term ward, two people were at home and one lived in a combination of nursing ward and home. The sample are referred to as participants, next of kin, or by their family role.

The study followed the guidelines for research ethics and was approved by the Norwegian Centre for Research Data NSD

(ref no. 345854). All participants gave informed written consent, and anonymisation was ensured by transcribing the interviews to safeguard privacy.

### Data collection and analysis

In the focus group interviews, we used an interview guide with open-ended questions to ensure a coherent narrative of experiences of social support. The interviews were conducted between January–May 2017. They lasted between one and one and a half hours and were recorded and transcribed verbatim. Both authors participated in conducting the interviews to ensure notes were taken during the interview situation. One of the researchers took on the role of moderator. The transcribed interviews with notes represented three different narratives that shed light on the aim of the study.

We used narrative analysis with a focus on thematic content analysis (Riessman, 2008). The analysis included four different readings. The first was an open, naive reading of all the data to form a complete picture of the content and communication process. The second was a thematic analytical reading resulting in key topics related to social support, which provided the main themes in the results: *Acknowledging dramatic change; Ensuring the right help at the right time; Self-taught social support*. The third reading was discursive and its main focus was on exploring and describing challenges and dilemmas in social support. Finally, a fourth interpretive reading of what was at stake in the participants' experiences of social support was conducted. The fourth reading refer to the conclusions that emerged in the description of the results and concerned: the importance of the family- and life course perspective, continuity in follow-up, and communicative competence in the follow-up of next of kin.

The variation of roles and sexes in the sample helped to achieve the goal of the study, which was to understand the experiences of social support for next of kin. The size and nationally defined sample are a limitation regarding the generalisation of the results. However, the narrative approach is a strength as it ensures a rich description of experiences (Riessman, 2008). The validity and credibility in studies are linked to the goal of knowledge development and transparency in the production of results (Kvale and Brinkmann, 2015). To ensure this, both researchers participated in all phases of the study and the results were discussed with research colleagues.

## Results

The analysis identified three overarching themes: *Acknowledging dramatic change; Ensuring the right help at the right time; Self-taught social support*.

### Acknowledging a dramatic change

The first overarching theme in the narratives was the importance of acknowledging the dramatic changes in the participants' everyday life. The participants described a demanding, ongoing everyday situation that was aggravated by various "phases". This ongoing dramatic change was so compelling for the participants to convey, that it was challenging to make them reflect on social support as a defined topic. They wanted to tell the whole dramatic story of what had happened in their own family.

The participants spoke about an increasingly demanding everyday situation that began with incipient concerns related to changes in behaviour, everyday skills and the conduct of the person with dementia. These participants gave examples:

**Table 1 – Sample description**

Focusgroup 1	Focusgroup 2	Focusgroup 3
Participant 1: Male; Spouse	Participant 1: Male; Spouse	Participant 1: Male; Spouse
Participant 2: Female; Spouse	Participant 2: Male; Spouse	Participant 2: Male; Parent
Participant 3: Female; Daughter	Participant 3: Male; Spouse	Participant 3: Female; Spouse
Participant 4: Female; Daughter	Participant 4: Male; Spouse	Participant 4: Female; Sibling
		Participant 5: Female; Parent

*There were very specific things that happened – for example: buying three cucumbers. She does not eat cucumbers! (father); Then she started more and more (...) unable to take care of herself, (...) forgot to get dressed (spouse). She wandered out at night (...) suddenly it started to become unsafe (daughter); It is tough to have 24/7 care (spouse).*

These concerns were often linked to challenging communication within the family and with the welfare system. Family members had different views on the severity and necessity of action.

The theme *Acknowledging dramatic change* is further based on the participants' stories of processing and grieving that someone close to them had suffered a serious illness. At the same time, everyday life became more and more demanding, and one had to work to obtain social support for oneself. The spouse of a man with early dementia said: *There is something about... it's your spouse, right, and then you see the decline in function. And then everyone says to you, oh... now you have to take care of yourself. How am I supposed to do that?*

Dramatic changes in everyday life are also linked to the participants' stories about the transition to a nursing home. These themes in the stories have a clearly before-and-now perspective; separating experiences into what happened before and after the transition to the nursing home. Everyday life with close family broke down due to the institution's routines, which represented both mental and practical relief, but at the same time often changed the continuity in next of kin relationships. A male spouse said: *Yes, from the fact that she ended up in the nursing home there, it is clear that we have a completely different life. I live at home alone; she lives over there alone.*

The results show that the participants described the development of social support from a family and life course perspective. Dramatic change as a characteristic of next of kin's experiences is based on a long time, often years, with breaches of expectations, lack of predictability, and risk in everyday life. The participants had been working to clarify the prospects of social support from family, friends and the health and care services. The participants experienced that social support, as they had known it before, was put to the test and changed.

### **Ensuring the right help at the right time**

The importance of ensuring the right help at the right time is the second recurring theme in the narratives of the participants. The participants focused on challenges related to attempts to ensure help, as well as a lack of continuity in follow-up and further help from public services.

Stories about contact with GPs and other service providers were inconsistent. Some people were met with understanding; others described practices that lacked coherence and commitment, as this adult daughter said: *The support system depends on the individual. (...) Seeing the whole person is a very important point.* The flow of information about the current services offered was described as very different among municipalities, service levels and service providers. Participants generally emphasised the importance of service providers being engaged and maintaining continuous contact in the follow-up.

Feeling lonely while waiting for examinations from GPs and the specialist health services was also pointed out as challenging. Many participants reported being alone with a challenging everyday life. *That waiting time, it has been the worst. (...) For a year and a half, no one kept in touch with us (spouse). Participants gave constructive suggestions for improvement, such as this spouse: (Provide) a dialogue partner early, and information early (...) so you do not feel completely alone.*

Challenges in getting people with dementia to accept help were also conveyed. Several participants experienced being alone with the motivational work: *My mother came to the day centre after a lot of discussion. (...) but then they called me, and she wanted to go home, and I had to come and get her (daughter).* Other participants conveyed successful collaboration about motivation to receive support, emphasising the importance of facilitated support. Standard solutions such as the day centre, dementia school, or home nursing do not suit everyone and are suitable at different times. *A day centre is not relevant for a 60-year-old man (spouse).*

The theme *Ensuring the right help at the right time* also refers to the participants giving constructive suggestions for improving the services for people with dementia in nursing homes: *These are the ones [our closest ones] we are thinking about (male spouse).* Relatives' experiences of social support, and the quality of life of the person with dementia were described as intertwined. Social support was described as a family matter.

The participants conveyed different experiences of how nursing home employees invited relatives to discuss expectations and their role as next of kin. This included questions about how they could participate in everyday life at the nursing home and contribute to the follow-up of the person with dementia. Lack of resources, the number of service providers, and physical and social activities in the nursing home were experienced as things that contributed to worry and experiencing inadequate social support in one's own everyday life. A male spouse put it this way: *This is not a good place for her. There is far too little going on. It's not a life.* Several next of kin emphasised that the experience of social support was also promoted by providing space for relatives to contribute.

The theme *Ensuring the right help at the right time* conveys a gap between the need for social support and the competence and facilities of family, friends and social services in promoting social support. Social support was described as relationally and contextually intertwined with the social support and quality of service offered to their loved ones. The participants emphasised the importance of involvement and participation, continuity and coherence in social support.

### **Self-taught social support**

The third theme analysed from participants' narratives refers to next of kin having to learn how to promote social support by themselves. This included different ways of interacting and communicating in both public and private arenas. They learned this new communicative competence of social support gradually and largely on their own.

The communicative competence included knowledge about how the available services are structured and organised, and what information is perceived as relevant in mediating services. To help document their everyday life challenges to the welfare services, the participants said they wrote diaries and logs about everyday life. This provided concrete examples to refer to during meetings regarding the needs in welfare services. One participant said: *If you present that log to a professional, then that professional will immediately be able to see that there are no interpretations here, (...) only observations.*

In the process of designing social support, training courses for next of kin were described as positive contributions. They provided an opportunity to ask questions about general topics, such as diagnoses, legal rights and relevant welfare services, and communication with people with dementia. Participating in courses for next of kin made it possible to experience direct social support through the exchange of experience, understanding and emotional support.



The participants also emphasised the importance of the group leader's competence in ensuring a dialogue in which everyone had their say and experienced being acknowledged. Others underscored that support groups must last longer than a few months, a "training course part 2" (...) with next of kin who have developed in relation to the disease (male spouse). Some participated in new discussion groups, group counselling, or dementia school along with the person with dementia. Involvement in user organisations, and sharing knowledge and experiences were also described as activities that helped to explore and develop social support over a longer period.

*Self-taught social support* also included experience in communicating with one's own siblings, relatives and siblings of the person with dementia, adult joint children, and the spouse's children, friends and neighbours. The participants referred to challenging conversations exploring the roles and functions of family members related to informing, organising everyday help and promoting relief, health and well-being for both the next of kin and the person with dementia. Some participants talked about how when friends withdrew from the relationship, they had visited them, explained the situation, and emphasised the importance of their friendship and social support.

The spouse of a man with early onset dementia spoke about how she had to teach herself, her family and her friends how they could best contribute support in the demanding situation. *I phoned his best friend and thanked him for visiting him for coffee (...), but I said I need you to pick him up when I'm at home.* The participants underscored the importance of organising time to be alone, continuing with some leisure activities, and allowing oneself to share the humour in everyday life as a means of experiencing emotional and social support. Participants also said that openness helped them to maintain relationships, and secrecy contributed to challenges in maintaining social networks. According to the participants, being open about the diagnosis of the person with dementia was a particularly challenging communicative skill. Several participants requested communicative help and support from welfare services.

*Self-taught social support* represented a significant part of the participants' stories. Social support (as they knew it from their previous lives) became inadequate and the participants described their challenges and creativity in a new life situation. In order to be able to collaborate with both a loved one showing behavioural changes, as well as family, friends and welfare services, next of kin had to learn concrete skills in communication that helped to strengthen their social network. In this study, the development of social support among the next of kin of people with dementia included both social and personal development related to communicating with different parts of their social network.

## Discussion

The discussion will present arguments to how the results of the study can improve the understanding of social support for next of kin of people with dementia.

### **Dramatic changes in family and life course**

The dramatic changes described by next of kin are characterised by long-term burdens, lack of predictability and insufficient social support. These factors entail physical and mental health challenges (Adelman et al., 2014; Brunvoll, 2017; Pérez-Cruz et al., 2019; Ringer et al., 2020). Studies that address health

challenges for next of kin, however, often have an individual symptom focus, where time-limited interventions are offered as an aid to individual stress management. These programmes point to inconsistent results (Bjorge et al., 2019; Chenoweth et al., 2016). In our study, the participants communicate in a family – and life course perspective, an approach with increasing focus and investigated in recent research (Clemmensen et al., 2019; Fjetland and Tokovska, 2020; Strøm and Dreyer, 2019).

The studies of Johannesen et al. (2017) and Clemmensen et al. (2019) describe three phases related to the development of symptoms in dementia as central to next of kin's experiences. The phases include the first period with anxiety and changes in the skills of the person with dementia, then efforts to design help and support for the changed everyday life, to a completely changed daily life for the family. The studies have parallels to the results of our study. In our study, however, the participants are more concerned with the tasks, functions and roles of next of kin, which change differently and at different times for each family. Clemmensen et al. (2019) refer to archetypal role types of family members. Our study emphasises that the dramatic change dementia causes for the family contributes to family roles that must be largely redesigned. Role changes are dynamic and linked to unique family situations rather than fixed role types.

Clemmensen et al. (2019) limited their study to the period when a relative with dementia is living at home. In our study the transition to nursing homes was described as a dramatic, "total", change involving demanding assessments of risk, new roles and changed family life; "a new life". The review study of Solvoll and Wang (2018) describes the experiences of next of kin as three chronological phases; "Entrance, stay and departure", each phase with its own set of challenges and resources (ibid.: 294). The experience of social support for next of kin in our study was conveyed in a family perspective with an emphasis on both everyday life and lifecycle perspective rather than as fixed phases or structures. The participants emphasised the importance of an adapted family understanding regarding the provision of social support. The person with dementia and each person among the next of kin is unique (with a unique everyday situation). This result is confirmed by other studies that question the benefits of standardised support programmes for the next of kin of people with dementia (Carter et al., 2020; Dam et al., 2016).

Based on this study, the next of kins' emphasis on being in a dramatic family situation represents a starting point for the further development of social support in welfare services. Furthermore, next of kin participating in this study emphasised the importance of service providers being able to adapt to each family's unique situation.

### **Social support as contact and continuity**

In this study, the challenge of ensuring the right help at the right time was a recurring theme. Personal commitment by service and welfare providers was emphasised by participants. This result is confirmed by other studies (Robinson et al., 2013; Strøm and Dreyer, 2019). Waiting for a medical assessment of dementia without continuity and follow-up from public services was pointed out as particularly burdensome. The provision of health and care services depends on a diagnostic process of revealing the disease. This can represent an individual patient focus that might contribute to loneliness and lack of social support for relatives (Dam et al., 2016). Loneliness is a significant public health challenge (Norwegian Ministry of Health and Care Services, 2019). A lack of family focus, and loneliness

during demanding waiting times were also highlighted by participants in the study by Strøm and Dreyer (2019).

According to our study, challenging waiting times are, to a very small extent, part of the health and care service's focus, despite guidelines that emphasise continuity, follow-up and involvement (Norwegian Ministry of Health, 2020a; WHO, 2017). The public guidelines have to some degree been incorporated in recent practice in public health care in Norwegian municipalities (Norwegian Ministry of Health, 2020a). This entails the establishment of a plan for dementia care, the use of a coordinator, a memory team and a contact person for next of kin to realize the plan. The importance of continued emphasis on including next of kin in planning processes and everyday care is confirmed by our study as well as other studies (Nakrem and Hynne, 2017; Solvoll and Wang, 2018).

### ***Self-taught social support as communicative competence***

This study contributes to knowledge about how next of kin develop social support in their own everyday lives. The participants described and justified what kind of knowledge, competencies, and skills they had to learn to take care of their own and their families' health, quality of life, dignity and social participation. The study shows how different aspects of social support – psychological, emotional and spiritual; informative, guiding and advisory; instrumental and practical help, assistance and support (Schieffloe, 2015) – involve social and communicative competence (Barton, 2007).

The participants gave examples of how they specifically worked to formulate what kind of support they needed. This involved initiative, as well as developing the ability to speak directly and make specific requests for help, support and relief, described by Eide and Eide (2017) as informative communication skills. These skills imply competence in understanding what kind of information a specific person in a specific context needs (Barton, 2007). The participants' emphasis on openness towards neighbours, friends and family are examples of informative communication skills. Other examples are the participants' suggestions to use descriptive language through log writing – as opposed to emotional and interpretive language – to justify their support needs to health and care personnel.

Another communicative skill that the study participants emphasised was the ability to discuss and tolerate disagreement. Eide and Eide (2017) describe these as exploratory communication skills. They included experiences of listening to other family members' opinions about what constituted the appropriate help. Exploring these communicative skills

contributed to both strengthened and broken relationships in relationships. Participants also emphasised knowledge about how to communicate with the person with dementia – in relation to both activities of everyday life and self-insight. This may be interpreted to include exploratory skills, affirmative and appreciative communication skills, and the ability to structure and lead conversations (Eide and Eide, 2017). Some participants called for assistance to talk about existential and spiritual meaning, as both research and theories emphasise as part of social support (Callaby et al., 2012; Meyer et al., 2015; Schieffloe, 2015; Wennberg et al., 2015).

The communicative competence in the understanding of social support that this study points to has been given little focus in research. However, there are several studies related to learning general coping strategies. Several of these studies have an individual focus on reducing symptoms of ill health and strain (Chenoweth et al., 2016; Donnellan et al., 2017; Gaugler et al., 2011), and not on interactions in everyday life. This study emphasises that social support must also be learned as a communicative practice and adapted to different arenas and new situations.

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## **Conclusions**

This study emphasises that social support is a contextual phenomenon related to the unique everyday life and social network of every family. It also emphasises the importance of acknowledging the dramatic change that the next of kin of a person with dementia experiences and strengthening the family and life course as a perspective in the development of social support. This study supports the importance of welfare services taking responsibility for contact and continuity in the follow-up of both the person with dementia and next of kin.

The new knowledge contributed by the study is that it is also important to take a communicative perspective to understand social support. Developing social support for next of kin involves exploring and learning new ways to communicate in different arenas and in different situations.

By strengthening the involvement of the next of kin themselves in the design of the strategies and support programs of the welfare services, the relevance and effectiveness of social support for the next of kin of people with dementia can be strengthened.

### ***Conflict of interests***

The authors have no conflict of interests to declare.

## „Potrebujem, aby si ho vyzdvihol.“ Skúsenosti so sociálnou podporou najbližších príbuzných osôb s demenciou

### Súhrn

**Úvod:** Demografické zmeny majú za následok zvyšujúci sa výskyt demencie. V dôsledku nesúladu medzi sociálnou podporou a záťažou starostlivosti v každodennom živote o chorého člena rodiny prechádzajú najbližší príbuzní problémami v oblasti zdravia. Cieľom štúdie bolo prispieť k poznaniu toho, čo charakterizuje skúsenosť a učenie sa sociálnej podpore medzi najbližšími príbuznými osôb s demenciou – a ako je možné tejto skúsenosti porozumieť.

**Metódy:** Štúdia má kvalitatívny dizajn. Výskumnú vzorku tvorilo trinásť osôb zúčastňujúcich sa na troch skupinových rozhovoroch: šesť žien a sedem mužov v rôznych stupňoch príbuzenstva, prežívajúcich rôzne fázy demencie svojho člena rodiny, a z rôznych vidieckych aj mestských obcí a miest v Nórsku. Štúdia bola schválená Nórskym centrom výskumných údajov a od všetkých účastníkov bol získaný informovaný súhlas. Rozhovory boli analyzované pomocou naratívnej analýzy spracované v štyroch fázach.

**Výsledky:** Účastníci výskumu popisovali celú svoju životnú situáciu. Poukázali na rozsiahle zmeny v ich životných situáciách počas dlhého obdobia, kde pretrvávala a menila sa potreba sociálnej podpory. Analyzovali sa tri tematické charakteristiky sociálnej podpory: *Uznanie dramatických zmien; Zabezpečenie správnej pomoci v pravý čas; a Samo(na)učenie sa sociálnej podpory.*

**Záver:** Na základe výsledkov štúdie je perspektíva životného cyklu, kontinuita a zameranie na komunikačné schopnosti pri zvyšovaní sociálnej podpory ústredným bodom skúsenosti so sociálnou podporou pre najbližších príbuzných osôb s demenciou.

**Kľúčové slová:** demencia; kvalitatívna metóda; najbližší príbuzní; skupinový rozhovor; sociálna podpora

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